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## **The SEIQoL and functional status:**

### **How do they relate?**

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## **ABSTRACT**

Over recent years, an emphasis has emerged in UK and international policy documents, over the involvement of people in the delivery of health care. However, evaluations of health services still largely rest on outcome measures that reflect professional concerns. As new health services are being developed, new patient-centred outcome measures are needed to evaluate them. This paper aims at exploring the possibility of individual quality of life as an outcome measure for health services. As a first step, it aims to elucidate the relationship of functional outcome measures to the Schedule for the Evaluation of Individual Quality of Life (SEIQoL), in groups of people whose age or medical diagnosis serve as the basis for health service design. Its objectives are to study the relation of SEIQoL scores and life areas to functional status in an older population and in a group of people with Chronic Obstructive Pulmonary Disease (COPD). Older people selected their health most frequently as one of the most important areas in their life (9.9%, versus 8.6% for people with COPD), and were more satisfied with it ( $U=2512$ ,  $p=0.007$ ). People's health status did not impact on the way they defined their quality of life, but on their level of satisfaction with discrete life areas. The weights attributed to health were significantly negatively correlated to people's overall quality of life score in the overall sample ( $\rho=-0.34$ ,  $p<0.001$ ).

In the light of recent national and international policy documents advocating for the development of new, more person centred health services, our results supports the proposition of the authors of SEIQoL, that individual quality of life measures have the potential to bring a significant contribution to the evaluation health services.

Key words: Individual quality of life, SEIQoL-DW, health status, COPD, older people, patient centredness, outcome measures.

## INTRODUCTION

Over the past few years, a new emphasis emerged in policy documents within the UK National Health Service (NHS), over the involvement of people in the delivery of care. In 1999, a White paper (1) initiated this movement by recognising people's ability to make decisions about their own health. In 2001 and 2002, two *Shifting the Balance of Power* (2, 3) documents set out the way to empower front line staff and service users. They advocate for changes in organisations and attitudes, so that front line staff are supported to develop their practice and increase patient centredness. From then on, patients should be considered as partners in their own care, and should be involved in the development and evaluation of new services. In 2004, *Putting People at the Heart of Public Services* (4) added to this move, putting the emphasis on offering "person centred and personalised" health services. In this document, older people are identified as having "a relatively high likelihood of chronic disease and long-term conditions" and it is stated that "they make heavy use of health care services". So people in general, and people with chronic conditions and older people in particular, are to be at the centre of health service development and delivery.

However, service or intervention evaluations still largely use outcome measures that reflect professional concerns and reduce and fragment people's experience. For example, rates of self-referral, speed of assessments or intervention and clinical or biological outcomes as well as measures of cognitive abilities (5, 6, 7, 8) have been used in research on older people. In a systematic review of factors influencing outcome in older patients admitted to hospital, Campbell et al. (9) used length of stay, mortality, discharge destination and readmission rate as outcomes. The National Centre for Health Outcomes Development (10) has produced recently a review of instruments measuring aspects of health and quality of life in older people. The

authors identified 33 instruments, which all assessed physical function, and most assessed psychological and social well-being. 15 of these were generic instruments, which “facilitate the identification of co-morbid features and treatment side effects that may not be captured by specific instruments” (10). The review supports the use of these generic instruments in “community dwelling older people, particularly those with lower levels of morbidity”. The emphasis is still therefore placed on clinical, rather than individual, relevance and when generic instruments are used, it is to focus on health rather than on people’s life as a whole. In relation to COPD, the emphasis of outcome measurement is focused even further on indicators of physiological function, perceived severity of symptoms and functional ability (11, 12, 13).

There is an apparent tension between the policy goals of person centredness, and the outcome measures used to evaluate health services, which continue to be driven by services’ concerns. Outcome measures tend to adopt a reductionist approach that obliterates people’s experiences of using services. As new health care services are being developed on the back of recent policy documents, new outcome measures will be needed to evaluate them, above and beyond the traditional functionally based ones. O’Boyle (14) proposed that health care services should be measured from the perspective of the patient, in terms of how services make a difference to day to day living, therefore complementing traditional measures based on disease status and mortality.

The Schedule for the Individual Quality of Life – Direct Weighting (SEIQoL-DW, 15) has been used in the studies discussed in this paper. It is a generic quality of life measure that operationalises quality of life as “what the person tells him / herself it is”

(16). When compared to other quality of life measures, it has been found to come closer to measuring the subjective and dynamic elements likely to have major influences on the life quality (17).

To date, the SEIQoL has been used in more than 200 studies, in over a dozen countries (16). In health related studies, it has been used in people suffering from peptic ulcer disease and irritable bowel disease (18), osteoarthritis (19), AIDS (20), cancer (21, 22), cystic fibrosis (23), stroke (24), multiple sclerosis (17), mental illness (25), amyotrophic lateral sclerosis (26, 27), people with leukaemia and lymphoma (28), people with End Stage Renal Failure (29), carers of people with dementia (30), and young people with diabetes (31) to name a few.

In spite of this growing body of literature, little is yet understood about the relationship of objective health status to subjectively assessed quality of life. This paper aims to elucidate this relationship, in groups of people whose age or medical diagnosis serve as the basis for health service design and provision (32). Its objectives are to study the relation of SEIQoL scores and elicited life areas in an older population and in a group of people suffering from Chronic Obstructive Pulmonary Disease (COPD). Descriptive statistics are used to study the relationship of quality of life scores and selected life areas to age, gender and disease severity.

## **METHODS**

### **Using SEIQoL**

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) assesses patients' judgements about what they value in relation to their own life quality (14). It is based on the propositions that quality of life should be assessed by self report, and that a person's judgement is constructed from an assessment of his or her level of satisfaction in discrete domains of life that they consider important (33). The SEIQoL samples each individual's profile in terms of life areas, and is idiographic, coherent and quasi-rational (16). It is based on Brunswik and Hammond's work on perception and the analysis of judgement (34, 35).

The Schedule for the Evaluation of Individual Quality of Life – Direct Weighing (SEIQoL-DW) (15) was used to measure quality of life in the two studies. The Direct Weighing procedure was developed following observations that in many situations, the complexity and time necessary to apply the full SEIQoL made it unsuitable (15). It is administered in the form of a semi-structured interview in three phases:

1. Cues elicitation: The respondent is asked to name the five areas of life (cues), which are of greatest importance to his / her overall quality of life.
2. Cues levels: The respondent rates current status against a vertical visual analogue scale labelled at the upper extremity 'as good as could possibly be' and at the lower extremity as 'as bad as could be'. These ratings (or cue levels) can range from 0 to 100.
3. Cues weights: A disc weighing system is used, which consists of five interlocking laminated circular discs of different colours on a percentage base scale. Each disc is labelled with one of the cues elicited by the respondent.



The discs are stacked above one another, and may be rotated independently over each other in such a way that on completion, one is left with a circle composed of different coloured segments each representing the weight given to a particular area of life. All five weights add up to a total value of 100.

Each cue level is multiplied by the corresponding cue weight and divided by 100 and the products are summed across the five cues to give a global SEIQoL score. This score can range from 0 to 100, with higher scores indicating greater perceived quality of life.

### **Data sources**

For the purpose of this paper, SEIQoL data was extracted from two research projects carried out by the authors. The studies were focussing on patterns of service use by older people (36) and people suffering from COPD (37). Trained researchers measured the SEIQoL along with other parameters, in order to provide a comprehensive description of the population studied and their use of available services. As described earlier, older people are seen as heavy users of health services, and these are developed specifically for their needs. COPD is a slowly progressive disease of the airways that is characterised by a gradual loss of lung function. The symptoms can range from chronic cough and sputum production to severe disabling shortness of breath. So people with COPD have a range of needs, and are likely to be heavy health service users, over extended periods of time. Health services are developed around the needs of these two patient populations, which makes them particularly relevant tracer populations for the use of patient centred outcome measures, such as individual life quality.

## **Older people**

The aims of the study were to survey older people within one locality, to identify their use of services and their perceived quality of life. Following approval from the Newcastle and North Tyneside Local Research Ethics Committee, participants were recruited from a health service database of all people registered with a general practitioner across two health authorities. These records provide a comprehensive list of all those aged 75 years and over. Invitations and written details were sent to 600 individuals, 214 individuals responded (35.7%) to initial and reminder letters. A cohort of 185 participated, representing a 30.8% participation rate. Data were collected using structured interviews at the beginning of the study and one-year later. 17 of these people were excluded from this analysis because they had a diagnosed respiratory condition. People's health status was assessed by self-report, as well as using the Multidimensional Health Assessment Questionnaire (38).

According to Pincus et al. (38) the MHAQ was developed to overcome the 'floor effects' of other scales in which patients may report normal scores although they experience meaningful functional limitations and psychological distress. The scale incorporates advanced Activities of Daily Living (ADL) such as 'can you walk two miles', 'can you run or jog two miles' or 'can you participate in games and sports as you would like'. It also includes psychological items, which screen for problems with sleep, stress, anxiety and depression. The addition of these components allows the older person to identify areas in which they experience functional limitations and psychological distress that would otherwise not be identified. The questionnaire comprises of eighteen questions, eight of which focus on the basic ADLs, six focus on

advanced ADLs and four on psychological aspects. Each questionnaire has a four-point response: without any difficulty (1), with some difficulty (2), with much difficulty (3), unable to do (4). The total overall score ranges from 18 to 72 with lower scores indicating better functioning. A score of 18, for example, indicates that a person can undertake all ADLs without any difficulty. Each of the three sections can be summed individually as follows: Basis ADL score ranging from 8 to 32, a score of 8 indicates no difficulty with ADLs, advanced ADL score range from 6 to 24, a score of 6 indicates no difficulty, and psychological score range from 4 to 16, with a score of 4 indicating no difficulty.

### **People with COPD**

This study aimed to document the range and frequency of services used by people with COPD, and to investigate the association with quality of life, psychological and biomedical variables. Participants were recruited from the respiratory medicine clinics of two acute NHS Trusts in the North of England, following approval from the Newcastle and North Tyneside Local Research Ethics Committee. Inclusion criteria were that participants should be aged 40 years or over, be current or previous smokers and have a Forced Expiratory Volume ( $FEV_1$ ) to Forced Vital Capacity (FVC) ratio less than 70% of predicted value and  $FEV_1$  less than 80% of predicted value. All individuals seeing a chest physician over a retrospective period of 12 months who met these inclusion criteria were invited to participate.

Invitations and written details of the study were sent to 424 individuals. 303 individuals responded and of these 189 participated, representing a 44.6% participation rate. Data were collected using structured interviews carried out in

participants' own homes. All interviewers had a health professional background and completed a two-day training programme.

The St George's Respiratory Questionnaire (SGRQ) (39) was used to measure health status and perceived well-being in this sample. This is a widely used standardised, self-completed questionnaire that assesses the severity of symptoms including cough, sputum production, shortness of breath and wheezing, as well as the effect that shortness of breath has on activities of daily living. The scale comprises 59 items categorised into three sub-scales. The symptoms sub-scale assesses distress caused by respiratory specific symptoms and comprises 8 items. The activity sub-scale, comprising 16 items, assesses the physical activities that cause or are limited by breathlessness and the impact sub-scale, which comprises 35 items, assesses the social and psychological effects of the disease. A total score can be calculated from the scores of all items and both the total and the sub-scale scores are expressed as percentages of the maximum possible. Higher scores indicate poorer health status.

### **Data analysis**

Non-parametric statistics have been used throughout the analysis reported here, due to the distribution of the main variables and due to the fact that they were mostly ordinal level data. The way in which the two groups defined their life quality, and the relative weight and level of satisfaction attributed to life areas were compared through a process of secondary analysis. The differences in which people from the two study groups assessed their quality of life were tested with Kruskal-Wallis and Mann-Whitney U tests. Spearman's rho was used to correlate weight and SEIQoL scores in groups of people having selected the same cue. Mann-Whitney U tests were also used

to assess the differences in levels and weights attributed to life areas by subgroups of study participants, and to determine the differences in quality of life scores between people having selected the same cues across the two study samples. The levels and weights attributed to the different cues were also multiplied in order to facilitate analysis; this gave us a weighted level of satisfaction, referred to as 'index' for each cue elicited.

## RESULTS

### SEIQoL score and functional status

#### INSERT TABLE 1 AROUND HERE

##### Older people

There was little difference in median quality of life score between men (82.5) and women (81.4), and this was not significant ( $U=3219$ ,  $p=0.969$ ). SEIQoL scores were not correlated to age in this group ( $\rho=-0.13$ ,  $p=0.40$ ). Health, as assessed by the MHAQ, was positively associated with respondents' own judgement of their health ( $p=0.000$ ). SEIQoL was significantly associated with self-determined health status ( $\chi^2=22.7$ ,  $p=0.000$ ). Of those people with higher than median quality of life score, 61.6% described their health as being below average, compared with 27.5% describing their health as above average ( $\chi^2=12.05$ ,  $d.f.=2$ ,  $p=0.002$ ). The MHAQ only weakly correlated to SEIQoL score ( $\rho=-0.27$ ,  $p=0.000$ ).

##### People with COPD

There was little difference in quality of life score between men (76.1) and women (73.0), and this difference was not significant ( $U=3104$ ,  $p=0.056$ ). SEIQoL scores were also not significantly correlated to age within this group ( $\rho=0.05$ ,  $p=0.55$ ). SEIQoL score was not correlated to the overall SGRQ score ( $\rho=-0.15$ ,  $p=0.12$ ). It was, however, significantly negatively correlated to the impairment subscale ( $\rho=-0.21$ ,  $p=0.01$ ) of the SGRQ.

### **SEIQoL cues and diagnostic group**

Table 2 shows the cues elicited by each of the study groups, along with the frequency with which each cue was elicited, and its mean index for the three study groups.

### **INSERT TABLE 2 AROUND HERE**

Overall, Table 2 shows more similarities than differences between the study groups. The frequencies at which cues were selected in the overall sample were: 'social network' (39.9%), 'hobbies' (20.5%), 'independence' (12.4%), 'health' (9.2%) and 'home' (5.6%).

Older people were generally more satisfied with their hobbies ( $U=9807$ ,  $p=0.000$ ), independence ( $U=4529$ ,  $p=0.008$ ), health ( $U=2512$ ,  $p=0.007$ ) and their home ( $U=743$ ,  $p=0.003$ ) than people with COPD.

### **SEIQoL cues and functional status**

An attempt was made to elicit whether health status impacts on the way people define their life quality. There were a few differences in the frequencies at which people with severe, moderate or mild COPD elicited their cues, and the two most commonly cited cues were social network and hobbies. People with severe and moderate COPD then elicited independence and health. This order was reversed for people with mild COPD, who elicited health more often than independence. The impairment subscale of the SGRQ was significantly correlated to SEIQoL score in people with COPD ( $\rho=-0.21$ ,  $p=0.01$ ). A further analysis showed that the levels attributed to cues were significantly correlated to the overall score of the SGRQ ( $\rho=-0.109$ ,  $p=0.009$ ) while the weights varied little ( $\rho=0.01$ ,  $p=0.81$ ).

There was very little difference in the frequencies at which older people who had assessed their health as poor, average or good elicited their cues. The order of frequency for the five most mentioned life areas (social network, hobbies, independence, health and home) was the same for the three groups. The MHAQ score was positively associated with respondent's own judgement of their health ( $p < 0.01$ ). SEIQoL was significantly, albeit weakly, associated with self-determined health status ( $\chi^2 = 114.4$ ,  $df = 4$ ,  $p = 0.000$ ). The MHAQ score was weakly correlated to cue levels ( $\rho = -0.26$ ,  $p = 0.000$ ), but not to weights ( $\rho = 0.004$ ,  $p = 0.91$ ). The MHAQ overall was negatively correlated to SEIQoL score ( $\rho = -0.274$ ,  $p < 0.01$ ). The association was not any stronger between the Advanced ADL ( $\rho = -0.270$ ,  $p < 0.01$ ), or psychological ( $\rho = -0.183$ ,  $p < 0.01$ ) subscales and the SEIQoL.



## DISCUSSION

This paper aimed at establishing the relationship of functional outcome measures to individual life quality in a population of people over 75 years of age and of people with COPD. The presence of a COPD diagnosis or the age group did not affect the most important life areas selected, and there seem to be a lot of similarities between our study groups and the general population. Indeed, although the life areas were labelled differently, there are obvious commonalities Bowling's study (40) and the one reported here: 'social network' or 'relationships with family and relatives', 'home' or 'standard of living / housing' and 'health' or 'own health or health of other people' were recurrent themes. In our study, social network was both the most frequently elicited cue, and the one attributed the highest index.

Individual quality of life and functional status did not correlate in any way, whether people had an official diagnosis or not. This is substantiated in the literature (41). Health was neither the most frequently cited, nor given the highest index. In the two groups, functional status did not impact on the way in which people defined their quality of life (the cues they chose). This has been evidenced in other groups in the literature: leisure, family and work were elicited significantly more often by patients than by healthy controls in a gastroenterology population, and rather fewer patients referred to health than did members of the healthy group (18). In a study looking at quality of life before and after a hip replacement operation O'Boyle et al. (19) found that only a few subjects nominated personal health as a crucial element in their quality of life, and that it was nominated more frequently by healthy controls than by patients. In our study, health status did not impact on the importance given to selected areas, but on the level of satisfaction attributed to these areas. In other words, people did not

define their life differently when their objective health worsened, but had a more negative outlook on these important life areas. This corroborates the results of studies conducted in Canada and the United States (42, 43), where the authors concluded that “the influence of health status on the quality of people’s lives is probably typically overestimated in studies narrowly focused on health and the quality of life” and that general health does not have a direct impact on participants’ satisfaction with their overall quality of life, but rather an indirect effect through their level of health satisfaction. This is a factor that the SEIQoL, whilst being ‘person centred’ and ‘user led’ to borrow notions figuring high on the health policy agenda in the UK, can measure. A lot of outcome measures commonly used in the evaluation of health services are medically based or functionally based, and thus reflect more the concerns of the service than those of its users. Other, more generic measures, tend to focus on the limitations on life quality inflicted by disease or treatment, and obliterate the broader realm of a person’s experience. Our results, in highlighting an important, albeit indirect, relationship between health and individual quality of life, support the view that individual quality of life measures could bring valuable insights to the evaluation of newly developed, more person-centred, services.

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*Table 1:* Study and health descriptors for the two study groups.

		COPD	Older People
N		187	168
Mean age (SD; range)		68.3 (10.0; 41 – 89)	80.6 (4.7; 75 – 95)
Sex ratio (M:F)		1.2	0.71
Median SEIQoL Score (interquartile range)		74.6 (19.3)	82.0 (15.7)
BTS ( % )	Mild	30.3	
	Moderate	33.3	
	Severe	36.4	
Mean (SD) FEV <sub>1</sub> (litres)		47.7 (17.8)	
Mean (SD) SGRQ		80.1 (17.0)	
Mean (SD) MHAQ score			10.9 (4.7)
Self assessed health	Excellent		6.5%
	Good		37.5%
	Average		31.0%
	Poor		14.5%
	Very poor		10.1%

*Table 2: Cues elicited in the study groups and mean levels, weights and indexes (level x weight)*

<b>Cues</b>	<b>COPD</b>				<b>Older people</b>			
	Freq (%)	Mean Level	Mean Weight	Index	Freq (%)	Mean Level	Mean Weight	Index
Social network	42.8	78.7	25.5	21.2	36.4	82.0	24.5	21.0
Independence	10.2	55.9	18.8	10.5	14.8	72.8	17.8	13.1
Health	8.6	47.8	27.4	13.4	9.9	63.9	26.1	16.9
Home	5.2	69.0	14.8	10.2	5.9	79.9	18.8	15.0
Hobbies	20.1	59.4	11.0	6.6	20.7	75.4	14.2	11.0
Work / study	1.6	58.4	15.3	8.7	0.5	75.0	12.3	9.2
Holidays	3.4	50.5	12.6	7.1	4.2	77.6	10.7	8.4
Inner self	2.2	70.3	17.3	12.1	3.4	83.7	19.8	17.2
Others	5.8	65.2	13.7	9.1	4.1	71.0	18.0	12.3